

UK Health Data Research Alliance Board – actions and meeting notes

Wednesday 20th July 2022 (15:00 – 17:00)

Immediate actions for Alliance members:

All Alliance members are asked to:

- Consider responding to Scotland's [Health and social care data strategy](#). The consultation period ends 12th August.
- Consider responding to Northern Ireland's [Data Strategy document](#). The consultation period ends 30th September 2022.
- Review the NIHR Clinical Research Network enterprise architecture technology vision presented by Sam Liscio and provide input on the direction of travel. Please contact Sam Liscio for more information via samantha.liscio@nihr.ac.uk.
- Provide feedback on the draft ICO consultation response document (Paper D). Email Cassie Smith via cassie.smith@hdruk.ac.uk.
- Help us define the future structure and governance for the Alliance and ways of working (paper F). We are looking for volunteers who could help us draft some options for consideration in advance of the October Board meeting. If interested, please email Stephen.Burrows@hdruk.ac.uk or ukalliance@hdruk.ac.uk.

Actions for HDR UK secretariat:

- Circulate slides presented at the meeting.
- Convene a working group to establish future governance of the Alliance.
- Consider how best to connect members of the Black Internship Programme to complement the work being delivered by Alliance members.

Meeting notes:

Welcome, introductions and opening remarks

Andrew Morris, Director of HDR UK, opened the meeting by welcoming new Alliance members, Cancer Research UK and UK Longitudinal Linkage Collaboration. Melissa Lewis Brown, CRUK Head of Research Data Strategy, announced the publication of [CRUK's Data Strategy](#) which was launched on 11th July 2022. Andrew also welcomed Professor Dame Anna Dominiczak who has been newly appointed as the new Scottish Chief Scientific Officer.



Action points from last meeting & Gateway report

Action points from the last meeting were briefly highlighted and reviewed.

Paola Quattroni, Head of Alliance Engagement and Strategy, HDR UK, invited all members to engage with the Innovative Gateway onboarding process. Paola thanked the members that are already doing so and encouraged anybody to reach out that needed support.

Paola provided a brief update on the 'Linking Data for Research' workshop that took place on 13th July 2022. This was chaired by Meredith Leston (Postdoctoral Researcher, University of Oxford) and provided presentations from stakeholders that hold unique perspectives on the issues around use of linked data for research, such as consent, legal requirements, public trust and communication. Outputs from this workshop will be shared with the Alliance board and published on the Alliance website.

Andrew thanked the Board members for their support and involvement with the Black Internship Programme. 41 Alliance members have taken part to support 82 Internships across the UK.

HDR UK recently hosted an in-person event on synthetic data which was delivered and received very positively. Outputs from the workshop will be shared via the website.

Updates from members and partners

Andrew welcomed Steve Kern, Deputy Director of Quantitative Sciences, Global Health, The Bill & Melinda Gates Foundation.

- Steve has been working with HDR UK on the international endeavours to support the safe and transparent use of data across all nations and enable data driven innovations.
- Steve highlighted a number of collaborative Grand Challenge projects that the Gates' foundation are working on. This figure is 53, reaching across 12 countries. In many countries, data is collected and stored but not shared intentionally to be used in a strategic way. Building on the work of the International COVID-19 Data Alliance (ICODA), the Gates Foundation hope to encourage better international collaboration and strategic use of health data to improve global health.

As part of the general updates, representatives from the UK nations provided a summary of recent work.

Michael Chapman and Simon Bolton provided updates from NHS England:

- The Data Saves Lives strategy was highlighted. This can be found [here](#). An additional comprehensive summary about both the data strategy and Goldacre review recommendations is provided by Jess Morley from the Bennett Institute [here](#).
- NHS DigiTrials have been very important in recruiting patients to the [NHS Galleri trial](#). The trial has recruited 140000 volunteers. This is an exemplar of how to rapidly complete trials when using routinely collected data.
- A commentary was recently published in the Lancet in collaboration with HDR UK colleagues on Data provenance and integrity of health-care systems data for clinical trials. This paper can be found [here](#).
- Building on the work with national core studies, NHS Digital is working on upgrading their secure data environment, which should be in public beta by October.



- NHS Digital are continuing to receive a high number of data access requests and are focussing on improvements of the system.
- The merger of NHS England and NHS Digital is ongoing and maintaining trust in how data is handled across the NHS during this merger is a primary focus.

Chris Orton provided an update from SAIL Databank and on behalf of Alexy Newberry from Welsh Government

- Good progress with Co-connect initiative. Infrastructure and governance are in place. Vaccine and testing data should be online by September.
- Federation work within the National Core Studies programme is ongoing and progressing well.
- Continuing to rewrite information governance review panel application forms to ensure direct API integration with Data Access Request forms on the Innovation Gateway.
- Ensuring as many projects as possible will be published in the SAIL Data Use register.
- General work is ongoing to pivot COVID-19 projects to become business as usual.
- Continuing to support UKLLC.
- Health and Care Research Wales have convened a 'Data for Research' working group to consider best approach for Wales on digital objectives on UK clinical research vision.

Scott Heald provided updates on behalf of Public Health Scotland

- Working with universities and recruiting PhD students for internships. There is a general lack of awareness of data science careers within the NHS. It was suggested that the Alliance members consider possible solutions and existing training models to address data science skills gaps within the NHS and social care settings.
- Scotland's [Health and social care data strategy](#) is open for consultation. The consultation period ends 12th August.
- There is currently a big focus on social care at Public Health Scotland and the intention is to bring the national care service in line with the national health service.
- Working with CRUK on how to better collaborate across the UK on cancer research.
- Building on data surveillance from Covid-19 to encompass other public health topics.
- The number of Data Access Requests is increasing and there is work being done to improve the service.
- Public Health Scotland are now part of Research Data Scotland.

Declan Bradley provided an update from Health and Social Care Northern Ireland

- Northern Ireland have also published a [Data Strategy document](#). The consultation period ends 30th September 2022. The document covers all health data and not just health research data.
- Working on federated cohort discovery. This will be used through SAIL Databank. The information governance processes for this are still being developed.
- There has been an increase in interest of Northern Ireland's datasets, from outside of Northern Ireland since they were added to the Innovation Gateway, which is positive to see.

Sam Liscio, Chief Technology Officer at NIHR Clinical Research Network, provided an overview of the NIHR CRN's Digital Strategy.



- The strategy principally endeavours to provide a single user interface for all NIHR platforms that is cooperative with other NHS services, such as the NHS app.
- To provide input on the NIHR CRN enterprise architecture technology vision, please contact Sam Liscio via samantha.liscio@nihr.ac.uk.

Trust and Transparency

Cassie Smith, Head of Legal, HDR UK presented an update on the Pan-UK Data Governance Steering Group.

- The purpose of the steering group is to provide expert advice on how to overcome major blockers to research productivity and how to streamline data governance to facilitate faster access to data in Trusted Research Environments.
- The steering group have identified three main priorities; undertake a mapping exercise to outline data access across organisations, develop a TRE/SDE legal toolkit and increase the adoption and understanding of the five safes data access application form. Potential future actions include precedent sharing, establishing a researcher passporting accreditation system and streamlining approval criteria.

HDR UK have drafted a response to the [ICO Anonymisation, pseudonymisation and privacy enhancing technologies guidance](#). The deadline for providing feedback is 16th September 2022. Please contact Cassie.Smith@hdruk.ac.uk to provide input.

DARE-UK exemplar project: Innovative involvement and governance to support public trust

Lucie Burgess, Research Data Hub Programme Director, Diabetes UK presented an update on the STEADFAST project. Lucie highlighted innovative ways to embed public involvement and improve understanding of use of sensitive data in research among young people.

GP Data for Planning and Research – update on public engagement and how Alliance members can support

Lorna Branton, Head of Communications, NHS England presented an update on NHS Digital General Practice Data for Planning and Research (GPDPR).

The presentation highlighted key findings from the NHS England survey, assessing public opinion around availability and use of GPDPR.

Joint work with NHS England Transformation Directorate

Tim Hubbard, TRE Workstream Lead (HDR UK) and Head of Medical and Molecular Genetics at Kings College London, provided an update on ongoing collaboration with NHS England. An updated version of the SDE policy guidelines outlined in the recent Data Strategy will be published in August.

Alliance developments – beyond the Industrial Strategy Challenge Fund

UK Health Data Research Alliance Gibbs Building, 215 Euston Road, London NW1 2BE
enquiries@hdruk.ac.uk | [@HDR_UK](https://twitter.com/HDR_UK) | ukhealthdata.org



Paola Quattroni, Head of Alliance Engagement and Strategy, HDR UK, highlighted the need for updating the Alliance model to reflect changes in the ecosystem and ensuring it is fit for purpose for the next phase of the Alliance's development. A working group will be developed to provide opportunity to input on Alliance governance and ways of working. A set of recommendations will be developed and presented at the next Alliance Board meeting in October. To get involved please email Stephen.Burrows@hdruk.ac.uk.

Next Alliance Board meetings

The next Alliance Board meeting will take place via Zoom on 14th October 2022 09:00 – 11:00. An invite has been circulated.

We also have 26th January 2023 13:00-15:00 held in the diary. Invites to follow.

Appendix

Attendees

Name	Organisation
Lynn Morrice	BHF Data Science Centre
Chris Orton	BREATHE / SAIL / Swansea University
Melissa Lewis-Brown	Cancer Research UK (CRUK)
Rob Stewart	DATAMIND / King's College London
Ann John	DATAMIND / Swansea University
Karen Rigby	Diabetes UK
Mark Avery	Gut Reaction / Cambridge University Hospitals NHS Foundation Trust
Nathalie Kingston	Gut Reaction / NIHR BioResource
Neil Walker	Gut Reaction / NIHR BioResource / Cambridge University Hospitals NHS Foundation Trust
Kate Blake	Guy's and St Thomas' NHS Foundation Trust
Andrew Morris	HDR UK
Claire Argent	HDR UK
Clara Fennessy	HDR UK
David Seymour	HDR UK
Edel McNamara	HDR UK



Hans-Erik Aronson	HDR UK
Lara Edwards	HDR UK
Nada Karrar	HDR UK
Paola Quattroni	HDR UK
Sinduja Manohar	HDR UK
Stephen Burrows	HDR UK
Tim Hubbard	HDR UK
Lucie Burgess	Helix Data Innovation
Declan Bradley	HSCNI
Nicola Armstrong	HSCNI
John Zurowski	iCAIRD
Neena Modi	Imperial College London - Neonatal Data Analysis Unit (NDAU)
Hilary Fanning	INSIGHT / University Hospitals Birmingham NHS Foundation Trust
Paul Mouncey	Intensive Care National Audit and Research Centre (ICNARC)
Vishnu Chandrabalan	Lancashire Teaching Hospitals NHS Trust (LTHTR)
Anthony Wilson	Manchester University NHS Foundation Trust
Claire MacDonald	Manchester University NHS Foundation Trust
Darren Lunn	Medicines and Healthcare products Regulatory Agency (MHRA) / CPRD
Stephen Lock	National Institute for Health and Care Research CRN
Dal Bansal	National Pathology Imaging Co-operative (NPIC)
Lorna Branton	NHS Digital
Michael Chapman	NHS Digital
Simon Bolton	NHS Digital
Joe Watts	NHS England Transformation Directorate
Samantha Liscio	NIHR
Deborah Griggs	PathLAKE
Andrew Percy	PIONEER / University Hospitals Birmingham NHS Foundation Trust



Scott Heald	Public Health Scotland
Steffen Petersen	Queen Mary University of London
Zoe Plummer	Renal Association
Tom Barlow	Scottish Government
Roger Halliday	Scottish Government / Research Data Scotland
Anna Dominiczak	Scottish Government / University of Glasgow
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Sam Organ	UK Health Security Agency
Guy Smallman	University Hospitals Coventry and Warwickshire
Tim Robbins	University Hospitals Coventry and Warwickshire